

Parent Advisory Group for East Of England Neonatal Operational Delivery Network - Written evidence (PRT0050)

We are the Parent Advisory Group for the East of England Neonatal Operational Delivery Network. We are submitting evidence for the Pre-term Birth Committee as part of the call for evidence as we are a group of parents and carers who all have lived experience of having a baby stay on a neonatal unit in the East of England. To support this submission, we have hosted multiple listening sessions for parents of pre-term babies to share their lived experience and have collated this into themes and used direct quotes throughout.

We would be happy to be contacted for any additional input relating to our lived experience.

Variation in care and health inequalities

Our group are very aware of the health and care inequalities within neonatal settings and are advocates for removing the barriers to high-quality care. We would like to see equitable care for babies and families of all backgrounds, with care tailored to individual needs. Within our group geographical inequity is very evident, that is inconsistency in care and service provision across different units, either from lived experience of being transferred between units or in discussion with other members where it is clear they had varying access to support. For example, some of our members were on units with psychological support but others had none. Some families were able to access free meals, whereas other units did not offer this. There were clear differences in parent involvement in their baby's care, "I was able to make up my son's feeds on one unit which I really enjoyed and then when he was repatriated to our home unit, we were no longer able to do this which felt really unsettling and a step away from being really involved in his care"

Primary prevention and treatment for preterm birth

Wider population awareness of pre-term birth

As previous neonatal parents we all feel that more could be done to increase awareness and understanding of pre-term birth and neonatal care. We know that the incidence of pre-term birth is 1 in 12, yet this topic still remains in the 'taboo' category. People should be exposed to the signs and symptoms of pre-term birth and be empowered to access maternity services when they have concerns regarding their pregnancy.

The need for this increase of awareness and understanding of pre-term birth is not only required for service users but the wider population. Society as a whole is not aware of the likelihood of having a pre-term baby nor are they aware of the longer-term impacts. 'You need employers to be far more aware. You need people talking about it to normalise the fact that there is premature births. We need people to understand the effects, when you say you've been in hospital for so many months, people still don't understand.'

Being listened to

We have heard numerous experiences of service users sharing how, during pregnancy, they contacted maternity services with concerns regarding their baby and report feeling that their concerns were dismissed. These points of contact could be missed opportunities to try and prevent pre-term birth or at least prolong the onset of pre-term labour. It can also result in service users feeling unable to express concerns and may begin to ignore their personal instincts relating to their pregnancy.

Secondary prevention and treatment for preterm birth

Lack of pre-conception exploration prior to subsequent pregnancies

Multiple Parent Advisory Group members shared how they received no support or exploration of cause following their first pre-term birth. This highlighted the inequity to support as parents felt it was only those who were confident and competent to be able to search for information, were able to access what was needed.

'If you've had a preterm baby, you need to have a debrief and someone to look into it. Don't just go Oh, your baby was small but we'll discuss it when you have another baby. No, I want to know how to prevent it, if possible, before I get to that stage not be just dismissed.'

'I was like, is anyone going to do anything about this? So, I self-referred myself to clinics in London because I did that research. It's only those that shout loud enough that know where to self-refer or can do the right research and then get the right specialist support.'

How postnatal care and psychological support for women who have given birth preterm and parents can improve outcomes

Parental wellbeing

Parents agree that it is absolutely necessary for their baby to be the priority, however, this does often result in a deterioration of their personal wellbeing. Parents often don't consume food or drink for many hours as they are unable to eat at their baby's cot-side and will choose to stay close to them. 'On far too many occasions we would just be starving hungry because we were doing cuddles with her and you couldn't eat at her bedside, so you ended up just, you know, gritting your teeth.' Adequate nutrition and hydration is essential for these families who are already in a vulnerable state and it is even more vital when mothers or birthing parents are expressing breast milk for their baby.

Mothers/birthing people can often ignore their personal postnatal health such as; changes in discharge, ongoing pain, caesarean wound healing, excessive bleeding, etc. This can lead to deterioration in physical health requiring extended hospital admission or readmission.

Exclusion of Fathers/non-birthing parent

We do have Father's input to our Parent Advisory Group and common thoughts are that they are excluded from decision making discussions and report how communication can feel solely aimed at the mother/birthing parent. There was also a recognition that they also require support to cope with having a baby born pre-term. 'They've got to just crack on, doing what they're meant to be doing and put that to the back of their mind as well as supporting you.' 'Mentally worrying about their baby, their self or caring for other children, it's a lot on our partners to try and juggle.'

Psychological support

Parents recognised the benefits of accessing psychological support on the unit, in terms of supporting both their wellbeing on the unit and in the community. However, not all had access to dedicated support.

Some parents were scared to access psychological support due to fears of being labelled as an 'unfit parent' or being identified as not coping. 'If I said no, I'm not coping or I'm having a bad time, I was literally terrified that they would say, right we're going to take your child away from you.'

Emotions

Feelings of apprehension were commonly experienced as parents labelled the neonatal journey as a rollercoaster, full of highs and lows. 'I never felt

I could settle and enjoy the small milestones as I always felt I was waiting for her to deteriorate.'

Families were aware of not only their own experiences but also those around them and would often compare with others. They would often feel they should be grateful and appreciate that their baby wasn't as sick as some of the other babies on the unit. 'I think I almost kind of did toxic positivity on myself because we were doing amazing in comparison. I felt I had to suppress my feelings and I would change how I responded to news because I was aware of what was going on around me.'

Reassurance from all staff in maternity and neonatal, in addition to formal psychological support is required for parents to be supported through a grieving process. Grief doesn't just relate to when a baby dies. It can include grieving the loss of the future they had planned, grieving their pregnancy, grieving the birth they had hoped for, grieving the loss of a baby shower and celebration of birth and the list can continue. 'I remember coming home and I was crying because I had no belly, like I should still be pregnant.'

Integration between neonatal care for babies born preterm and postnatal care for women

Collaboration across maternity and neonatal

We know that maternity and neonatal services are commissioned differently and may be within different divisions within the hospital environment. However, the services are interlinked and the care they provide should be a continuum to those using the services. 'They're separate services, but there's got to be a really good link to make them seem like one for the service user because we need both at the same time.'

Basic needs

The lack of integration between postnatal care and neonatal care was evident when we discussed basic needs such as; medication, food, and vital signs monitoring. 'I was being reprimanded for not being on the postnatal ward when they come to do my observations but I was with my baby.' 'I definitely missed every day's medication but surely it wouldn't have been too much trouble for the midwife to say I needed to come down for it.'

Lack of empathy

Parent Advisory Group members felt that some maternity staff lacked empathy and compassion towards their current circumstances. 'How do we get those people to understand and communicate in a way so we're not stressed about being in a different place to our baby.' Parents expressed how it would be beneficial for maternity staff to have exposure to a neonatal care environment to support their understanding of how families are feeling during this time.

Being on a maternity postnatal ward without your baby is a truly distressing experience for parents. 'I just laid and cried as I could hear babies crying and I didn't have mine with me.'

Lack of expressing support

Early expression of breastmilk is vital for pre-term babies, if parents choose to do so. Advice and support is required to facilitate hand expressing within maternity services. Parents shared experiences of not receiving adequate advice or support and weren't aware that their body could produce colostrum when their baby was born pre-term. 'It was great because I was in a side room away from newborn babies, but I just felt like I was one less person they had to worry about. I felt because I didn't have my baby with me, they thought I didn't need support with breastfeeding.'

Peer support

Having support from other neonatal families on the unit or following discharge can bring a sense of community and support to families. Units can establish these connections by offering group sessions on the unit or in the community. 'We had a weekly group called cake and chat, where we could just talk and share our experiences.'

Longer term impacts, care and support for pre-term babies and their families.

Parents physical wellbeing.

Parents may experience deterioration with their personal physical wellbeing due to a lack of hydration, nutrition and restorative sleep, throughout their baby's admission on a neonatal unit. 'I didn't sleep as I was having awful nightmares that I'd never had before, or because I was having to wake up to express milk, or because I was getting a call from the hospital to say she'd have to be intubated again.'

Psychological impact.

Parents report having a delay in processing their trauma and found it was approximately 12-18 months after their neonatal journey that they began to feel the full psychological impact from their neonatal stay. 'Looking back, I think I should have had some counselling on the unit but I didn't want to go and speak about my feelings because she was the one going through it, not me. But then it hit me. It must have been when she was about 18-months-old and I was diagnosed with PTSD.'

Parents of a pre-term baby often experience feelings of guilt and describe feeling that their body had 'failed' their baby. 'I knew it wasn't right for a baby to be born that early and I still think to myself what did I do wrong?'

Health anxiety

Parents have ongoing concerns about the impact the neonatal care admission had on their baby. 'I still think of the effects of those medications she was given in neonatal care. I still wonder will it increase her chances of cancer later on. It really worries me.'

Parents reported feelings of heightened anxiety regarding their child's physical health and often access primary care and emergency services for conditions such as; moderate temperature and reflux. 'When you go to A&E, there should be a red flag saying they were a neonatal baby. You're looked at like this neurotic mother.'

Health implications

We know from recent research that 50% of Paediatric Intensive Care Unit admissions of under 2-year-olds, have had a previous stay on a neonatal unit. This demonstrates that for many neonatal families, their child will have ongoing health implications. Many of our Parent Advisory Group members children have had hospital readmissions and this causes other challenges as they are exposed to a different hospital environment.

Neonatal outreach

Our members recognised the beneficial input provided by neonatal outreach teams, not only for their baby, but to support them, as parents, with the transition to home. 'If I didn't have the outreach team, I would have really struggled because I would have found it really, really hard to go from being in NICU every day for three months to nothing.'

School

Children born pre-term are often vulnerable to infections, therefore, school attendance can be impacted, and parents expressed feeling pressured by schools. 'Like, what's the right thing to do when there's pressures they have to be in school, but if they're in school, they get poorly, like it's the impossible challenge.' 'It's not that I don't want my kid in school, but they are genuinely poorly, their lungs are still weak and I don't want them getting admitted to hospital again. How can we look after our kids best and how can we deal with that mentally?'

Children born pre-term often have developmental challenges and/or Special Educational Needs and although there are resources available to schools, parents often report a lack of understanding and awareness of the longer-term implications of being born pre-term and therefore a lack of support in educational settings.

Family

Parents report finding it difficult to manage the balance between parent vs carer as their child may have additional healthcare and support needs such as; tube feeding, dressing changes and stoma care, etc.

Traumatic experiences can have a negative impact on relationships within the family set-up leading to changes in relationships or a complete breakdown. Parents express this can be due to the difference in coping mechanisms and/or both parents experiencing psychological health issues.

Many families are fearful of having more children following a baby born pre-term, as evidences shows that you have an increased chance of experiencing pre-term labour again.

Financial

We know from evidence provided by Bliss that neonatal families face additional costs of approximately £405 per week. 'The cost of being in neonatal care was one big element of why we got into huge financial difficulty when my son was born prematurely in 2018. We're only just really in any sort of financial recovery in the last 9 months. Not only did we risk losing where we lived, but we ended up with mounting debt - not exactly the sort of stress you want to have on top of a neonatal stay and premature infant with all the stuff that comes with that.'

Fathers and non-birthing parents often have to return to work whilst their baby is still in neonatal care. Even mothers and birthing parents who are self-employed face this dilemma. This has a detrimental impact on implementing family integrated care and parent to child bonding.

Parents may have to leave their current careers due to their child requiring one-to-one care or having additional healthcare and support needs. Childcare establishments may not feel comfortable providing the level of care required, therefore, parents face difficult decisions to leave their career to prioritise the care of their child.

Institutionalised

Parents who have a longer stay on a neonatal unit can become institutionalised and struggle to cope with the transition to home. 'I kept a daily record for a year after she was discharged from NICU. I had it in columns and it was all her nappy changes, oral intake, what activities we had done that day, sleep. It wasn't until someone pointed out that you're like, oh yeah, that's not normal behaviour, is it?'

Parents reported being reliant on monitoring and seeking that reassurance once home from the neonatal unit. 'You're used to that monitoring, that data all the time, beeping, telling you she's OK. You go home to silence and you're told to learn to read your child, don't rely on the monitors. That's entirely sensible, I understand that, but that does

not satisfy my emotions. We had two monitors on the go at the same time, but it's because of bad anxiety.'

Isolation

After discharge from neonatal care, parents often experience feelings of isolation. Community groups and resources may not feel inclusive for families with a baby born pre-term and parents often feel they receive unwanted attention and sympathy when out in the public. They may receive unsympathetic comments such as 'At least you got to sleep whilst they were in hospital', 'Are you sure they are that age.' Comments like these and the unwanted attention due to baby having medical equipment such as oxygen tubing or Naso-Gastric tube feeding, can lead to families choosing not to socialise and therefore become segregated.

The fear of being surrounded by people with contagious conditions is another reason families choose to isolate themselves. They often feel continually anxious that their baby could become ill again and be re-admitted to hospital.

Missing out

Families often spend extended durations of time whilst their baby is in neonatal care, that by the time they get home, their maternity leave is drastically reduced. 'I spent nearly six months in and out of hospital and only had six months to actually spend time and do quality things with my baby. And you feel like you've been cheated out of it.'

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